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ABSTRACT

The material in this manual was selected to help non-therapists carry out feeding activities with children who have a neuromuscular disorder such as cerebral palsy. The manual attempts to develop the following competencies: selecting foods of an appropriate consistency, ensuring that the child is positioned correctly for feeding, feeding a child appropriately with a spoon, feeding a child appropriately with a cup, using strategies that facilitate normalcy of oral motor patterns, citing precautions to be considered during feeding a child with oral motor dysfunction, and recognizing the role of the therapist in developing and monitoring the child's feeding program. The importance of feeding to nutrition, socialization, communication, and pre-speech development is noted. A developmental sequence of feeding, a general progression of difficulty in chewing and swallowing food, and seven references are included. (JDD)

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Considerations for Feeding Children Who Have a Neuromuscular Disorder

Sandra Hall, Nancy Cicirello,
Penny Reed and Judith Hylton

TIES: Therapy In Educational Settings

A collaborative project conducted by Crippled Children's Division — University Affiliated Program, the Oregon Health Sciences University and the Oregon Department of Education, Regional Services for Students with Orthopedic Impairment. Funded by the U.S. Department of Education, Office of Special Education and Rehabilitative Services, grant number G008630055.

September 1987

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CONSIDERATIONS FOR FEEDING CHILDREN WHO HAVE A NEUROMUSCULAR DISORDER

Sandra Hall, Nancy Cicirello
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September 1987

PREFACE

INTRODUCTION

This manual was developed for people who want to follow well developed practices as they carry out feeding activities with a child who has a neuromuscular disorder such as cerebral palsy. The material in the manual was selected for non-therapists - teachers, instructional aides and parents -who carry out feeding activities. While this manual can help caregivers to better understand the feeding needs of a child, it is recommended that they **regularly consult with a therapist about changes in the child's needs.** Input from a therapist specially trained in oral-motor concerns and treatment is essential to management. Many occupational therapists and speech-language pathologists as well as some physical therapists have this training. In this manual the term "therapist" refers to a professional any one of the three disciplines who has had special training in oral motor treatment. Therapists may find this manual to be a valuable adjunct to their own demonstrations with the child as they help others learn to assist the child with feeding.

Eating is a fundamental activity for each individual. It is an activity that is nourishing, stimulating, social and communicative for each of us. The child with cerebral palsy needs to experience, as normally as possible, all of these factors that comprise the activity of eating. Because he may lack skill in controlling his oral musculature, he presents additional considerations for the feeder. This manual provides the caregiver with information pertinent to these unique needs and can assist the caregiver to become a knowledgeable feeder.

Cerebral palsy affects the child's ability to perform skilled motor activities. His oral motor abilities may be either underdeveloped or influenced by primitive reflexes and pathology, manifested by poor oral coordination.

Much of the mystery of feeding the child with cerebral palsy will be solved if you will do three things:

1. Analyze the way that you take a bite of food and a sip of liquid. What is your mouth doing? Your tongue? Your lips? When do you breathe and when do you swallow?

2. Imagine yourself to be unskilled in eating and a stranger is feeding you. What are your abilities and what do you know about the feeder? How do you communicate? How hungry are you? How fast do you like to eat? What do you like to eat or drink first at a meal? Are you comfortable with your feeder?

3. Read this manual.

BACKGROUND

Project TIES: Therapy in Educational Settings is a collaborative effort conducted by the University Affiliated Program of the Child Development and Rehabilitation Center at The Oregon Health Sciences University; and the Oregon Department of Education, Regional Services for Students with Orthopedic Impairment. Project TIES was funded by the US Department of Education, Office of Special Education and Rehabilitative Services, grant number G008630055. The goal of this three year project is to develop training materials for physical therapists and occupational therapists who work in schools with students who have a severe orthopedic impairment.

Topics for the training materials were determined through a series of formal and informal needs assessments by therapists practicing in schools in Oregon. Project staff then grouped the identified needs into topical categories and determined the format that would best convey the content of each topic.

The training materials were developed primarily for therapists who are new to the unique demands of the school setting or who have had little experience with children who have a severe orthopedic impairment. Other people such as administrators, teachers, aides and parents will find these materials helpful in understanding what therapists do and the rationale behind their efforts to integrate students' therapy programs into the larger context of their educational programs.

Since September of 1987, the project has completed six manuals and two videotapes:

A Model Plan for the Supervision and Evaluation of Therapy Services in Educational Settings

Considerations for Feeding Children who Have a Neuromuscular Disorder

Selected Articles on Feeding Children who Have a Neuromuscular Disorder

Teaching Nontherapists to do Positioning and Handling in Educational Settings

Teaching Nontherapists to do Positioning and Handling in Educational Settings video

The Art of Coaching: Training Nontherapists in the Physical and Functional Management of Students video

The Role of the Physical Therapist and the Occupational Therapist in the School Setting

The Therapist's Role In Adapted Physical Education

ACKNOWLEDGEMENTS

Many people contributed their expertise, time and support to this project. We especially want to thank our field readers for their well considered comments and suggestions. Our field readers for this manual were:

Lynn Lucas, Teacher of Orthopedically Impaired, Regional Program for Students with Orthopedic Impairment, Eugene, Oregon

Merry Meek, Speech-Language Pathologist, Crippled Children's Division-University Affiliated Program, Portland, Oregon

Judy Rowe, Occupational Therapist Registered, Regional Program for Students with Orthopedic Impairment, Holladay Center, Portland, Oregon

We also thank the physical and occupational therapists in schools throughout Oregon who field tested these materials and offered many valuable suggestions for their improvement. We thank our fine support staff, Sharon Pearce, Dee Rauk-Besel and Jessie Taylor, for their efficiency and good humor even while typing revisions of revisions. And we thank the children in Oregon's schools who have taught us how we learn.

We are grateful to Dr. Gerald Smith, Director of Training, University Affiliated Program at Oregon Health Sciences University and to Patricia Ellis, Associate Superintendent of Special Education, Oregon Department of Education, whose vision was essential to the inception of this undertaking and whose support vastly contributed to its successful execution.

We are indebted to Allan Oliver, Art Director of the OHSU Design Center for his fine work and infinite patience in developing a cover design and

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September, 1989

In writing this manual we have chosen to avoid awkward word combinations such as (s)he and his/hers, and instead have selected to refer to children as "he," therapists, teachers and aides as "she," and supervisors as "he." We hope the reader will accept this style and find it comfortable, for that is our intent.

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COMPETENCIES

Upon completing this manual the reader will be able to demonstrate the ability to:

1. select foods of a consistency that are appropriate for children who have different feeding requirements;

2. ensure that the child is positioned correctly for feeding;

3. feed a child appropriately with a spoon;

4. feed a child appropriately with a cup;

5. use strategies that facilitate normalcy of oral motor patterns;

6. cite precautions to be considered during feeding a child with oral motor dysfunction;

7. recognize the role of the therapist in developing and monitoring the child's feeding program and rely upon her for guidance as you carry out a feeding program.

FEEDING - WHY IS IT IMPORTANT?

NUTRITION	A child needs proper nutrients for growth, development and good health. Some children who are on feeding programs may require additional meals or snacks.
SOCIALIZATION	Feeding time is a social time. It is usually a pleasant social experience; between mothers and babies it is a bonding experience. Feeding time may be the only time the whole family is together during the day!
COMMUNICATION	During feeding the child can exert some control over his environment - which food he would like, when he wants it and when he has eaten enough. A child's response to food is a form of nonverbal communication that we need to acknowledge and respond to.
PRE-SPEECH	Eating involves movement patterns similar to those used in speech development. Good feeding programs work to improve oral-motor skills, which are important for the development of the musculature necessary for speech acquisition.

INTERVENTION

EVALUATION	The therapist assesses the oral-motor development and function of the child with feeding concerns.
PLANNING	Members of the IEP team plan a school feeding program for the child that can be carried over into the home.
IMPLEMENTATION	The therapist demonstrates proper feeding techniques to the person responsible for feeding the child.
CONSULTATION	The therapist consults with the feeder regarding such things as making necessary program changes, suggesting or providing adaptive equipment and answering questions.

FOOD - WHAT TO THINK ABOUT

SENSORY	Avoid mixing different types of foods within a single serving. This makes sensory discriminations between color, texture and taste difficult for the child.
TEMPERATURE	Keep cold foods cold and hot foods hot so the child can experience differences in temperature. Note that very hot and very cold foods may be overstimulating to some children.
NUTRITION	A balanced diet is a must for a healthy child. Vitamin supplements recommended by the pediatrician or nutrition consultant can be added to food.
TEXTURE	Provide food in a consistency that the child can manage orally, while giving him variety. Thickened foods are easier to manage than liquids. Pureed foods are easier to manage than solid foods. Avoid foods that could block the airway such as chunks, hot dogs, unmashed grapes, or foods with skins such as unpeeled apples.

EFFECTS OF DIFFERENT FOODS

1. Flavors involving sweet, sour, salty or acid citrus tend to increase saliva.

2. Milk tends to thicken saliva; beef or chicken broth tend to thin it.

3. Thin liquids are more difficult for the child to manage orally. Thicker liquids such as milk shakes or "smoothies" are easier to swallow.

4. Combinations of solids and liquids such as soup with noodles tend to be more difficult and confusing for the child to handle. Blend them together.

5. Slightly cooked vegetables and fruits such as apples, pears, green beans, carrots and broccoli with a firm consistency are easier to chew than raw vegetables.

6. Teeth are unnecessary for chewing semi-solids.

EQUIPMENT SUGGESTIONS

1. Towels and washcloth for cleaning the child.

2. Teflon coated or Tupperware spoon with a shallow bowl to prevent damage and discomfort to the child if he bites hard.

3. Cut-out cup of soft plastic with small rim. The diameter of the cup should match the child's mouth size.

4. Plastic straws when appropriate.

5. Equipment to maintain food temperature if feeding requires a prolonged time.

6. Bib to keep child's clothing clean.

7. Adaptive equipment and appropriate seating system to maintain posture for eating.

CONSIDERATIONS FOR THE FEEDER

1. You should be in a comfortable position when you assist a child in feeding.

2. When possible, sit directly in front of the child at an equal height to encourage eye contact and social interaction.

3. Maintain a pleasant facial expression and voice. The child's ability to sense your feelings about feeding will affect his performance.

4. Make feeding a pleasant experience by giving praise and encouragement to the child.

5. Encourage the child to communicate during the meal by allowing him to indicate which foods he wants and when. Time your conversation so that it will not excite abnormal patterns that interfere with the child's chewing and swallowing.

6. Be sensitive to the needs of the child, noting such things as when he has eaten enough and when he needs to rest.

7. Allow the child to be an active participant and to be as independent as possible during feeding.

8. Feeding a child involves a trusting partnership. Avoid changing feeders whenever possible. Be sure <u>any</u> replacement feeder has been well trained.

POSITIONING

1. BEFORE FEEDING

   Correct positioning will significantly influence the child's ability to normalize his oral-motor control. It is most important that the child be relaxed and positioned correctly in his chair or adaptive equipment.

   A. Hips should be well seated in chair with pelvis at neutral and well supported at sides.

   B. Feet should rest on a surface.

   C. The body should be symmetrical, with head in midline.

   D. The spine should be straight with the head and neck aligned to maintain the esophagus and airway in a line perpendicular to the shoulders and hips.

   E. Forearms should be positioned at nipple level on a raised tray or rolled towel to keep the shoulder slightly forward and encourage better body alignment.

2. DURING FEEDING

   Positioning may be accomplished with adaptive equipment such as corner chair, bolster chair, bean bag chair, wedge lap cushion for a baby, wheelchair or other conventional methods. The therapist can suggest appropriate equipment.

   Correct positioning should be maintained throughout feeding:

   A. hips and knees at 90 degree angles when seated

   B. feet supported

   C. shoulders slightly forward with arms well supported

   D. spine straight

   E. head in midline and bent slightly forward

   F. knees slightly apart

EXAMPLES OF POSITIONING FOR FEEDING

Figure A. A foam wedge or pillow to help a very small child stay in midline and maintain social contact with his feeder

Figure B. High chair that can be adapted with an insert or a sling seat for child with poor trunk control

Figure C. Corner chair for child with poor trunk control

Figure D. Wheelchair with adaptations for the older child who is unable to sit in a standard chair

CORRECTING POSITIONING FOR FEEDING

INCORRECT

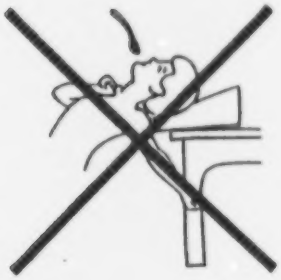

Figure E. Head and shoulders out of alignment.

Figure F. Head, back, arms and legs are stiff or extended.

Figure G. Body is stiff or extended.

CORRECT

Head is in midline and forward; shoulders are forward.

Hips, knees and ankles are at 90 degree angle, head is forward.

Head is at midline and symmetrical. In this illustration, the child is resting against a pillow. A rigid support such as a cookie sheet placed behind the pillow helps keep the child's back straight.

HOW TO FEED

I. SPOON FOODS

A. Place only a small amount of food on the front half of the spoon.

1. Never use a light plastic or wooden spoon as it can be broken by the child's bite. Tupperware and Mothercare spoons can be expected to withstand the child's biting.

2. Use a shallow-bowled spoon that is an appropriate size for the child's mouth.

B. Make sure the child's head is centered with his chin pointing down. Present food at the midline rather than from above or from the side. Child should be "ready," i.e., relaxed, with mouth closed.

C. Take the spoon straight into child's mouth, then, if necessary, press down on the middle of the tongue with the bowl of the spoon. Avoid hitting the teeth with the spoon.

D. Wait momentarily for lip closure on the spoon.

E. Remove food from spoon by withdrawing it straight out. If child bites down on the spoon, wait. Don't try to pull it out until child relaxes his jaw. A slight up and down movement of the spoon or turning the child's head and shoulders slightly may help him relax his jaw.

1. Discourage the child from removing food from the spoon with his teeth. Keep the spoon level and avoid scraping food off onto the teeth or the upper lip. You may assist him by flexing his head forward slightly.

2. Oral control techniques may be useful for some children; others resist their use. Ask the therapist for a demonstration before using the following:

F. Whenever possible, close the lips and wait for a coordinated swallow. When the child has cleared his mouth, present another bite.

II. BITE FOODS

Place a small strip of a soft solid food such as egg, cheese, cookie, soft sandwich or canned pear on the side of the mouth between the gums or teeth. This will encourage the tongue to lateralize, or move from side to side to get the food. Alternate placing food on each side of the mouth. For the child who does not lateralize his tongue, place a bit of food in his cheek pocket on the outside of his lower molars. Again alternate sides.

III. CUP

Pour a small amount of liquid into the cup. Be sure the child is well positioned and relaxed before presenting the cup. Many children become excited on seeing the cup in anticipation of a drink. If you lose control of the child, put the cup down and recollect him before proceeding. It is important to begin with lips closed.

A. Place the rim of cup between the child's lips, always in front of his teeth. The liquid should touch his upper lip, on top of the tongue. You may need to use oral control and/or pressure on the sternum (chest bone).

B. Gently tip the cup and allow only a small amount of liquid into the mouth, monitoring the breathing pattern. The child should not be exhaling while you pour the cup. The child will take in a small amount of liquid as he pauses for a breath. He should attempt by closing his lips to move the liquid from the front of the mouth to the back, in preparation for swallowing.

C. If the child is unable to close his lips, facilitate closure by positioning your hand as follows: middle finger under chin gently pushing up (avoid tip of chin), and, index finger or thumb on botton edge of lower lip gently pushing up.

While doing these two procedures, it is strongly recommended that the child's upper lip remain free. Attempting to get closure by additionally applying pressure to the upper lip may result in a primitive withdrawal by the child. Further, the mechanically assisted closure is unlikely to generalize into voluntary closure.

1. Discourage biting of the cup by not placing it in or behind the teeth.

2. If the child bites the cup, help him relax by bringing his shoulders forward. Speak softly and wait for biting to cease before removing the cup.

IV. CLEANING UP

Feeding a child can be a messy experience and as feeders we tend to want to tidy up as we go. However, constantly wiping a child's face can be overstimulating and should be avoided. An occasional gentle blot around the lips with a dry washcloth will do.

NOTES ON FEEDING

Although these techniques may seem awkward and confusing to you at first, guidance from a therapist and a little practice will increase your confidence and skill.

As you begin to gain skills, it is important that you communicate to the child what you expect of him. During the feeding, you might use phrases such as "When you are ready, I'll give you a drink." If the child has learned that "ready" means relaxed body with head in midline and lips closed, he will begin to respond to this cue, thus incorporating what he has learned into a self controlled response.

Independent feeding involves a variety of advanced skills. That topic is beyond the scope of this manual. However, many principles such as proper positioning and appropriate feeding equipment carry over into self feeding programs. Consult with the child's therapist before beginning self feeding programs.

PRECAUTIONS

1. CHOKING

   The possibility of choking is present at every feeding. A child with abnormal oral-motor control depends on the feeder to keep him safe. (Some children have special procedures listed. Find out!) **Practice responsible and knowledgeable feeding techniques and know the first aid techniques to alleviate choking.** If the child has recurring episodes of choking, check with the therapist who may want to refer the child for a medical evaluation.

2. SEIZURES

   The mouth is a very sensitive area and eating may induce seizure activity. If a seizure occurs, stop feeding momentarily and wait until the seizure is under control. Check to see if any food is in the mouth during and after seizure.

3. BEST PRACTICE

   Always use best feeding practices when feeding the child with cerebral palsy. The child depends on you to be skilled.

OTHER TYPES OF FEEDING

Gavage, Nasal-Gastro or Tube Feeding (any feeding other than oral) are nursing procedures. Do not use these techniques unless you are specifically trained in them.

APPENDIX A

FEEDING: DEVELOPMENTAL SEQUENCE

This developmental sequence of feeding indicates a general age at which normally developing children acquire different feeding skills. There is a good deal of variation in normal development however, and these ages are not exact. Some children whose development is within the normal range will acquire some skills earlier than is indicated in this sequence and some will demonstrate them at a later age.

AGE	SKILL
0-4 months	Strong oral reflexes (suck-swallow, rooting, gag). Incomplete lip closure, especially at the corners of the lips. Unable to voluntarily release the nipple.
1-2 months	Better lip closure. Tongue moves with jaw. Suckling - tongue moves up and down, in and out when sucking.
3 months	Mouth opens or tongue protrudes in anticipation of feeding.
4 months	Recognizes bottle. Suckling strength increases with body of tongue starting to raise and lower. More variety of tongue movements and less "reflex" movement. Looses liquids from sides of mouth during sucking. Cup drinking may be introduced. Messy, tongue may thrust with cup. Appetite may be erratic.
5 months	Mouth opens for spoon. May thrust his tongue involuntarily after spoon is removed and eject food.
6 months	"Munches," jaw moves up and down. Biting lacks rotary chewing. Tongue lateralization begins at 6-7 months, uses tongue to move food side to side. True suck, stable jaw, tongue moves up and down and "pumps." Upper lip comes down well on spoon. Finger feeding begins (6-8 months).

8 months	Tongue elevation with stable jaw, can channel liquids. Transfers food well from center of mouth to sides; rotary chewing begins, retains some vertical motions. Feeds self finger foods, messy. Holds own bottle. Makes many sounds while eating.
12 months	Controlled bite through food. Chews adequately. Rotary chewing fashion continues to improve until age three. Plays with tongue - sticks out experimentally. More choosey about food, very independent.
15-18 months	Begins spoon feeding, may spill. Drinks well from cup, stabilizes muscles around jaw. Licks lower lip.
21-24 months	Holds small glass with one hand. Inserts spoon without inverting it. Food preference may stem from taste, form, consistency or color.
3 years	Fork feeding begins. Pours liquids.
4 years	Sets table. Serves self. Washes and dries own face and hands.

APPENDIX B

GENERAL PROGRESSION OF DIFFICULTY IN CHEWING AND SWALLOWING FOOD

Thick liquids - such as fruit nectars, slushes, milk, milkshakes and infant formulas. Yogurt or applesauce can be added to juice to thicken it.

Strained foods - foods such as commercial baby foods, pureed or finely-blended table foods, smooth applesauce, pudding and yogurts.

Thickened foods - baby cereals, cream of wheat, and strained foods, thickened with semi-solids such as wheat germ, pudding, powdered protein or cornstarch.

Fork-mashed foods - cooked potatoes, squash or other vegetable, bananas or other soft fruit, and boiled egg.

Textured semi-solids - tapioca pudding, oatmeal and scrambled eggs.

Soft solids - whole cooked vegetables or fruit, boiled or fried eggs, cake, bananas, noodles, graham crackers, fish, steamed or chopped meats.

Solids - meats, firm cheeses, raisins and chicken.

Other solids - beef, hamburger casseroles, spaghetti with meat sauce, cottage cheese, raw vegatables or crunchy fruits, fresh fruit and sandwiches. These foods are thought of as being lumpy, crunchy, chewy or sticky.

FOODS THAT ARE THE MOST DIFFICULT TO CONTROL FOR A CHILD WITH POOR ORAL-MOTOR COORDINATION OR A HYPERSENSITIVE MOUTH.

Thin liquids - water, tea, coffee, bouillon or broth.

Combination foods - vegetable or noodle soup, gelatin with fruit or marshmallows, ice cream with nuts and "junior" baby foods.

APPENDIX C

EXAMPLE OF CLIENT NOTE PAGE

Child's Name _____ BD _____ Dx _____

Equipment needed

_____ _____

_____ _____

_____ _____

Positioning

_____

_____

_____

Feeding procedures and techniques

_____

_____

_____

_____

Food likes/dislikes

_____

_____

_____

Ways child communicates

_____

_____

Precautions

_____

_____

GLOSSARY OF TERMS

care giver	any person who provides care for the child
esophagus	passageway for food from the mouth to the stomach
facilitate	techniques that make more normal movement possible for the child
lateralize	to move to the side
neuromotor	relationship between the nervous system and the muscles as they affect motor output
normalize	to make more normal through the application of therapy techniques
oral-motor coordination	interaction of the muscles of the neck, lips, tongue, cheeks and jaw to produce smooth movement in eating
primitive	reflexes that are present in the normal infant and fade, but remain in the child with neuromotor concerns
smoothie	a fruit drink that has the consistency of a milk shake, usually pureed fruit combined with ice cream or yogurt

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